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ABSTRACT

A diagnostic evaluation for a person with suspected Alzheimer's disease is usually initiated by family members whose concerns go beyond strictly medical issues. To determine precisely what questions families want answered, a 15-point questionnaire was developed at a multi-disciplinary geriatric assessment clinic. Caregivers were asked to rate each question according to how important it was that the question be answered during the evaluation. Questions had to do with: (1) cause and treatment of the patient's symptoms; (2) patient's prognosis; (3) behavioral management; (4) family decision-making; (5) patient activity level; (6) institutionalization; and (7) use of community resources. The results of 50 consecutive questionnaires showed that the most important question to caregivers was, "What can we expect the future course of the illnes to be?" The type of question rated as important was found to vary according to patient's sex, caregiver's relationship to patient, patient's residence, and whether the patient's dementia had been previously diagnosed. Ways in which professionals can use the findings to provide caregivers with the type of information they need most are discussed. The questionnaire and tables of responses are appended. (NB)

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ASSESSING CAREGIVER INFORMATION NEEDS: A BRIEF QUESTIONNAIRE

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A diagnostic evaluation for a person with suspected Alzheimer's Disease is usually initiated by family members whose concerns go beyond strictly medical issues. So that professionals can more effectively address caregiver concerns, a brief questionnaire was developed and administered to caregivers of 50 consecutive patients with dementia who were seen for evaluation at a multi-disciplinary geriatric assessment clinic. Patients ranged in age from 59 to 86, with a median age of 75.8.

Fifteen questions (Appendix A) were selected for the questionnaire, based on the clinic team's observations of the concerns expressed by caregivers who were seen at the clinic in its first 1½ years of operation and on an article by Hayter (1982) in which she tabulated questions most frequently asked by 100 caregivers of Alzheimer patients who called her for information.

Prior to the initial clinic appointment, the questionnaire was sent to the caregiver who had initiated the evaluation, asking them to rate each question from "1" to "5" according to how important it was for the clinic team to answer that particular question during the evaluation. The questionnaire was then returned to the clinic so the staff could use it as a guide during the testing and during a discussion with the caregivers of the clinic's findings and recommendations.

A ranking of the questions according to the percentage of caregivers who rated the question "1" or "2" (High Importance) appears in Table 1.

Most caregivers (98%) wanted to know what the future course of the illness would be.

Caregivers also wanted to know about the cause of the patient's symptoms (88%) and whether everything had been done to find out if the symptoms were treatable (88%). The latter question was found by the clinic team to be particularly important because 68% of the patients seen at the clinic had already been diagnosed by another physician as having some type of dementia. It appeared that many of these caregivers came to the clinic because they had not been given an explanation of how the previous diagnosis had been arrived at.

While the three most frequently asked questions were medical in nature, the study shows that professionals must also be prepared to answer questions about managing behavior problems (86%), helping the patient use his or her abilities (76%), and knowing how much the patient can do for themselves (74%).

Table 2 ranks the questions of lowest importance to caregivers (questions rated as "4" or "5"). The low interest in guardianship may have occurred because the question presupposes that caregivers understand that dementia may create numerous types of legal complications.

Several characteristics of the caregiver and patient were evaluated to determine how they might affect the ranking of the question. The following tables illustrate these variables:

Table 3 - Caregiver's Relationship to Patient

Table 4 - Patient's Living Situation

Table 5 - Patient's Sex

Table 6 - Patient's Prior Diagnosis (of a dementing illness)

Questions which showed a difference of at least 25 percentage points are indicated by an asterisk. These are some of the findings which resulted when patient and caregiver variables were taken into account:

1. Questions most frequently rated as highly important were similar for spouse and adult child caregivers, however, more adult children expressed interest in learning about services (community services, nursing home care, financial assistance, guardianship) than did spouses.
2. Interest in financial assistance and community services was surprisingly low among caregivers of patients still at home.
3. Caregivers of male and female patients differed in the types of questions asked. The differences may be due in part to age (females were likely older) and also due to expectations regarding male and female roles.
4. It might be expected that caregivers of patients with no prior diagnosis of dementia might be interested primarily in the strictly medical issues of cause, treatability, and course. On the contrary, these caregivers were very interested in helping the patient use his or her abilities and in managing behavior problems.

Use of the questionnaire has enabled the clinic team to provide more in-depth attention to the special areas of concern noted by caregivers and to address areas which previously were often not directly brought up by caregivers in unstructured interviews. The questionnaire could also be used by:

1. Physicians, who in their office practices are increasingly being called upon to perform evaluations for persons with dementia and to provide caregivers with information.

2. Facilitators of caregiver support groups, to identify topics for program meetings.
3. Professionals who are providing counseling to family caregivers, to periodically assess caregiver concerns.
4. Social workers in hospitals, long term care facilities, adult day care programs, and home health agencies, to assist in referring family caregivers to other community services.

APPENDIX A

Please let us know how important it is for us to answer the following questions for you in this evaluation.

	High Importance				Low Importance
How much can we expect the patient to do for themselves?	1	2	3	4	5
Has everything possible been done to find out if the patient's symptoms are treatable?	1	2	3	4	5
How can we help the patient to best use their abilities?	1	2	3	4	5
What is the cause of the patient's symptoms?	1	2	3	4	5
What can we do about certain behaviors that may cause problems (like false ideas, agitation, not eating, forgetting, hiding things, etc.)?	1	2	3	4	5
Should the patient move to a higher level of care (i.e., from home to nursing home or from one level or nursing care to another?	1	2	3	4	5
What community services such as home health aids, sitters, or day care are available for the patient?	1	2	3	4	5
Does the patient need a guardian, conservator, or other legal protection?	1	2	3	4	5
What is the patient's life expectancy?	1	2	3	4	5
How can our family best come to an agreement over how to care for the patient?	1	2	3	4	5
Are the patient's medications correct?	1	2	3	4	5
Can the patient's illness be inherited by other family members?	1	2	3	4	5
What financial assistance is available to help pay for the patient's care?	1	2	3	4	5
What recreational or social activities would be best for the patient?	1	2	3	4	5
What can we expect the future course of the patient's illness to be?	1	2	3	4	5
Other, _____	1	2	3	4	5

ALL ANSWERS ARE CONFIDENTIAL

TABLE 1

Percentage of caregivers rating the question as "1" or "2" (High Importance)

N=50

What can we expect the future course of the patient's illness to be?	98%
Has everything possible been done to find out if the patient's symptoms are treatable?	88%
What is the cause of the patient's symptoms?	88%
What can we do about certain behaviors that may cause problems (like false ideas, agitation, not eating, forgetting, hiding things, etc.)?	86%
How can we help the patient to best use their abilities?	76%
How much can we expect the patient to do for themselves?	74%
Are the patient's medications correct?	68%
What recreational or social activities would be best for the patient?	64%
How can our family best come to an agreement over how to care for the patient?	58%
Can the patient's illness be inherited by other family members?	56%
What is the patient's life expectancy?	54%
Should the patient move to a higher level of care (i.e. from home to nursing home or from one level of nursing care to another)?	54%
What financial assistance is available to help pay for the patient's care?	52%
What community services such as home health aides, sitters, or day care are available for the patient?	38%
Does the patient need a guardian, conservator, or other legal protection?	36%

TABLE 2

Six Questions rated by caregivers as "4" or "5" (Low Importance)

N=50

Does the patient need a guardian, conservator, or other legal protection?	36%
Should the patient move to a higher level of care (i.e. from home to nursing home or from one level of nursing care to another)?	36%
Can the patient's illness be inherited by other family members?	24%
What is the patient's life expectancy?	24%
What community services such as home health aides, sitters, or day care are available for the patient?	24%
What financial assistance is available to help pay for the patient's care?	20%

TABLE 3

Percentage of spouses, adult children, and other caregivers (usually nursing home personnel) rating the question "1" or "2" (High Importance)

	Spouse	Adult Child	Other
	N=20	N=25	N=5
What can we expect the future course of the patient's illness to be?	95%	100%	100%
What is the cause of the patient's symptoms?	85%	92%	80%
Has everything possible been done to find out if the patient's symptoms are treatable?	85%	88%	80%
*What can we do about certain behaviors that may cause problems (like false ideas, agitation, not eating, forgetting, hiding things, etc.)?	75%	92%	100%
Are the patient's medications correct?	75%	68%	60%
*What is the patient's life expectancy?	75%	44%	20%
*How can we help the patient to best use their abilities?	65%	84%	100%
How can our family best come to an agreement over how to care for the patient?	65%	56%	N/A
How much can we expect the patient to do for themselves?	60%	84%	80%
What recreational or social activities would be best for the patient?	60%	64%	80%
Can the patient's illness be inherited by other family members?	45%	64%	60%
What financial assistance is available to help pay for the patient's care?	40%	60%	60%
*Should the patient move to a higher level of care (i.e. from home to nursing home or from one level of nursing care to another)?	25%	76%	60%
What community services such as home health aides, sitters, or day care are available for the patient?	25%	48%	40%
*Does the patient need a guardian, conservator, or other legal protection?	10%	56%	20%

*Questions for which responses differed by 25 percentage points or more.

TABLE 4

Percentage of caregivers of patients living at home and in nursing homes who rated the question "1" or "2" (High Importance)

	At Home	Nursing Home
	N=41	N=9
What can we expect the future course of the patient's illness to be?	98%	100%
*Has everything possible been done to find out if the patient's symptoms are treatable?	93%	22%
What is the cause of the patient's symptoms?	90%	78%
What can we do about certain behaviors that may cause problems (like false ideas, agitation, not eating, forgetting, hiding things, etc.)?	83%	100%
How can we help the patient to best use their abilities?	78%	78%
How much can we expect the patient to do for themselves?	73%	78%
Are the patient's medications correct?	66%	78%
What recreational or social activities would be best for the patient?	61%	78%
Should the patient move to a higher level of care (i.e. from home to nursing home or from one level of nursing care to another)?	56%	44%
How can our family best come to an agreement over how to care for the patient?	56%	55%
What is the patient's life expectancy?	51%	66%
*Can the patient's illness be inherited by other family members?	51%	78%
*What financial assistance is available to help pay for the patient's care?	46%	89%
Does the patient need a guardian, conservator, or other legal protection?	34%	33%
What community services such as home health aides, sitters, or day care are available for the patient?	27%	22%

*Questions for which responses differed by 25 percentage points or more.

TABLE 5

Percentage of caregivers of female and male patients rating the question as "1" or "2" (High Importance)

	Female	Male
	N=32	N=18
What can we expect the future course of the patient's illness to be?	100%	94%
*What can we do about certain behaviors that may cause problems (like false ideas, agitation, not eating, forgetting, hiding things, etc.)?	97%	67%
What is the cause of the patient's symptoms?	91%	84%
Has everything possible been done to find out if the patient's symptoms are treatable?	89%	89%
How can we help the patient to best use their abilities?	81%	72%
How much can we expect the patient to do for themselves?	75%	72%
What recreational or social activities would be best for the patient?	69%	55%
*Can the patient's illness be inherited by other family members?	65%	39%
Should the patient move to a higher level of care (i.e. from home to nursing home or from one level of nursing care to another)?	59%	45%
What financial assistance is available to help pay for the patient's care?	59%	39%
Are the patient's medications correct?	55%	78%
*How can our family best come to an agreement over how to care for the patient?	47%	78%
*Does the patient need a guardian, conservator, or other legal protection?	47%	17%
*What is the patient's life expectancy?	43%	72%
What community services such as home health aides, sitters, or day care are available for the patient?	40%	34%

*Questions for which responses differed by 25 percentage points or more.

TABLE 6

Percentage of patients who had no diagnosis of dementia, a diagnosis of Alzheimer's Disease (AD), or a diagnosis of hardening of the arteries, senility, arteriosclerosis, organic brain syndrome or memory loss due to old age prior to their initial clinic visit.

	None	AD	Other Dementia
	N=16	N=7	N=27
*What is the cause of the patient's symptoms?	100%	71%	85%
What can we expect the future course of the patient's illness to be?	100%	100%	96%
*How can we help the patient to best use their abilities?	94%	57%	70%
What can we do about certain behaviors that may cause problems (like false ideas, agitation, not eating, forgetting, hiding things, etc.)?	88%	100%	81%
Has everything possible been done to find out if the patient's symptoms are treatable?	88%	71%	93%
How much can we expect the patient to do for themselves?	75%	86%	70%
Should the patient move to a higher level of care (i.e. from home to nursing home or from one level of nursing care to another)?	63%	43%	52%
*How can our family best come to an agreement over how to care for the patient?	63%	86%	48%
*What recreational or social activities would be best for the patient?	63%	0%	63%
Are the patient's medications correct?	63%	86%	67%
What financial assistance is available to help pay for the patient's care?	57%	57%	48%
What is the patient's life expectancy?	57%	43%	56%
*What community services such as home health aides, sitters, or day care are available for the patient?	44%	14%	41%
Can the patient's illness be inherited by other family members?	44%	57%	63%
*Does the patient need a guardian, conservator, or other legal protection?	32%	14%	41%

*Questions for which responses differed by 25 percentage points or more.

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